

LIVING WITH HIV/AIDS



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This booklet is for people who are infected with the human immunodeficiency virus (HIV) and for their friends and families. HIV is the virus that causes acquired immunodeficiency syndrome (AIDS).

Although infection with HIV is serious, people with HIV and AIDS are living longer, healthier lives today, thanks to new and effective treatments. This booklet will help you understand how you can live with HIV and keep yourself healthy.

You probably have many questions about HIV, such as

- What is HIV and how did I get it?
- What is the difference between HIV infection and AIDS?
- How long does it take to go from HIV infection to a diagnosis of AIDS?
- How can I stay healthy longer?
- What can I expect when I go to the doctor?
- What is the treatment for HIV or AIDS?
- What are some of the other diseases I could get?
- How do I protect other people from my HIV?
- Is there special advice for women with HIV?
- Where can I find help in fighting HIV?

This booklet will give you answers to these questions. You can also ask your doctor any questions you have about HIV. Other sources of information about HIV are listed at the back of this booklet.

What is HIV and how did I get it?

HIV is the virus that causes AIDS. The first cases of AIDS were identified in the United States in 1981, but the virus probably existed here and in other parts of the world for many years before that. In 1984, scientists proved that HIV causes AIDS.

Ways you might have gotten HIV

- having unprotected sex (sex without a condom) with someone who has HIV
- sharing a needle to inject drugs or sharing drug works with someone who has HIV
- having a mother who was infected with HIV when you were born
- from a blood transfusion (However, it is unlikely you got infected that way because all blood in the United States has been tested for HIV since 1985.)

Ways you did NOT get (and no one else can get) HIV

- just working with or being around someone who has HIV
- being stung or bitten by an insect
- sitting on toilet seats
- doing everyday things like sharing a meal

What is the difference between HIV and AIDS?

HIV is the virus that causes the disease AIDS. Although HIV causes AIDS, a person can be infected with HIV for many years before AIDS develops.

When HIV enters your body, it infects specific cells in your immune system. These cells are called CD4 cells or helper T cells. They are important parts of your immune system and help your body fight infection and disease. When your CD4 cells are not working well, you are more likely to get sick.

Usually, CD4 cell counts in someone with a healthy immune system range from 500 to 1,800 per cubic millimeter of blood. AIDS is diagnosed when your CD4 cell count goes below 200. Even if your CD4 cell count is over 200, AIDS can be diagnosed if you have HIV and certain diseases such as tuberculosis or *Pneumocystis carinii* [NEW-mo-SIS-tis CA-RIN-nee-eye] pneumonia (PCP).

There are general stages of HIV infection that you may go through before AIDS develops.

- **Infection.** The earliest stage is right after you are infected. HIV can infect cells and copy itself before your immune system has started to respond. You may have felt flu-like symptoms during this time.
- **Response.** The next stage is when your body responds to the virus. Even if you don't feel any different, your body is trying to fight the virus by making antibodies against it. This is called seroconversion, when you go from being HIV negative to HIV positive.
- **No symptoms.** You may enter a stage in which you have no symptoms. This is called asymptomatic infection. You still have HIV and it may be causing damage that you can't feel.
- **Symptoms.** Symptomatic HIV infection is when you develop symptoms, such as certain infections, including PCP.
- **AIDS.** AIDS is diagnosed when you have a variety of symptoms, infections, and specific test results. There is no single test to diagnose AIDS.

How long does it take to go from HIV infection to a diagnosis of AIDS?

There is no one answer to this question because everyone is different. Estimates of the average length of time for progression from HIV to AIDS are being developed. Before antiretroviral therapy became available in 1996, scientists estimated that AIDS would develop within 10 years in about half the people with HIV. Since 1996, new medical treatments have been developed that can prevent or cure some of the illnesses associated with AIDS, though they cannot cure AIDS itself.

Various factors, including your genetic makeup, can influence the time between HIV infection and the development of AIDS.

Time between HIV infection and AIDS

Shorter

- older age
- infection with more than one type of HIV
- poor nutrition
- severe stress

Longer

- closely adhering to your doctor's recommendations
- eating healthy foods
- taking care of yourself

What is clear is that you have some control over the progression of HIV infection.

How can I stay healthy longer?

There are many things you can do for yourself to stay healthy. Here are a few.

- Make sure you have a health care provider who knows how to treat HIV. Begin treatment promptly once your doctor tells you to.
- Keep your appointments. Follow your doctor's instructions. If your doctor prescribes medicine for you, take the medicine just the way he or she tells you to because taking only some of your medicine gives your HIV infection more chance to fight back.



If you get sick from your medicine, call your doctor for advice; don't make changes to your medicine on your own or because of advice from friends.

- Get immunizations (shots) to prevent infections such as pneumonia and flu. Your doctor will tell you when to get these shots.
- Practice safe sex to reduce your risk of getting a sexually transmitted disease (STD) or another strain of HIV.
- If you smoke or use drugs not prescribed by your doctor, quit.
- Eat healthy foods. This will help keep you strong, keep your energy and weight up, and help your body protect itself.
- Exercise regularly.
- Get enough sleep and rest.
- Take time to relax. Many people find that meditation or prayer, along with exercise and rest, help them cope with the stress of having HIV or AIDS.

There are also many things you can do to protect your health when you prepare food or eat, when you travel, and when you're around pets and other animals. You can read more about these things in the brochures in the CDC Opportunistic Infection series. You can get these brochures and other information about HIV by calling CDC-INFO at 1-800-232-4636 or by going to the CDC Internet address, www.cdc.gov/hiv/dhap.htm.

What can I expect when I go to the doctor?

During your first appointment your doctor will ask you questions, examine you, take a blood sample, and do some other tests. Your doctor also may do a skin test for tuberculosis and give you some immunizations (shots).



Tell your doctor about any health problems you are having so that you can get treatment. You also should ask your doctor any questions you have about HIV or AIDS, such as

- what to do if your medicine makes you sick
- where to get help for quitting smoking or using drugs
- how to create a healthier diet
- how to minimize the chance that you will spread HIV to your partners

Your blood sample is used for many tests, including the CD4 cell count and viral load. Your **CD4 cell count** tells you how many CD4 cells you have in your blood. If you are getting treatment, your CD4 cell counts indicate how well it is working. If your CD4 cell count rises, your body is better able to fight infection. **Viral load** testing measures the amount of HIV in your blood. Your viral load helps predict what will happen next with your HIV infection if you don't get treatment.

Keep your follow-up appointments with your doctor. At these appointments you and your doctor will talk about your test results, and he or she may prescribe medicine for you.

What is the treatment for HIV or AIDS?

- **Antiretroviral medicines.** Because HIV is a certain type of virus called a retrovirus, the drugs used to treat it are called antiretroviral medicines. These powerful medicines control the virus and slow progression of HIV infection, but they do not cure it. You need to take these medicines exactly as your doctor prescribes.
- **HAART.** The current recommended treatment for HIV is a combination of three or more medicines. This regimen of medicines is called highly active antiretroviral therapy (HAART).

How many pills you will need to take and how often you will take them depends on which medicines your doctor chooses for you. Remember, each HAART regimen is tailored to each individual patient. There is no one best regimen. You can read more about specific HAART regimens at www.aidsinfo.nih.gov/other/cbrochure/english/04_en.html.

HAART may cause some side effects. You and your doctor should discuss potential side effects so that you will know if they occur. If you experience any side effects, even those that may seem minor, you should talk about them with your doctor.

- **Other medicines.** Your doctor may also prescribe other medicines for you, depending on your CD4 cell count. Always discuss any side effects with your doctor. Never change the way you are taking any of the medicines without first talking with your doctor. If you don't take your medicines the right way, they may not be as effective as they should be.
- **Treating other infections.** If your HIV infection gets worse and your CD4 cell count falls below 200, you are more likely to get other infections. Your doctor may prescribe medicines to prevent particular infections, such as PCP.

The most important thing you can do after you learn that you have HIV is to work closely with your doctor. Because HIV and HIV-related illnesses vary from person to person, your doctor will design a medical care plan specifically for you. To help your doctor make the best choices for you, you must tell your doctor about any side effects or symptoms you have.

What are some of the other diseases I could get?

Because HIV damages your immune system, you may have a higher chance of getting certain diseases, called *opportunistic infections*. They are so named because an HIV-infected person's weakened immune system gives these diseases the opportunity to develop. Fortunately, people with HIV who are taking HAART can go a long time before their immune system is damaged enough to allow an opportunistic infection to occur. That's why it is so important to get tested and start treatment early. Many people may not know they have HIV until AIDS and an opportunistic infection develop. Many germs can cause opportunistic infections.

Examples of common opportunistic infections

Common name	Full name	Pronunciation
PCP	<i>Pneumocystis carinii</i> pneumonia	NEW-mo-SIS-tis CA-RIN-nee-eye
MAC	<i>Mycobacterium avium</i> complex	my-ko-bak-TEER-i-um AYE-vee-um
CMV	Cytomegalovirus	si-to-MEG-eh-lo-vi-res
TB	Tuberculosis	too-burr-qu-LO-sis
Toxo	Toxoplasmosis	tok-so-plaz-MO-sis
Crypto	Cryptosporidiosis	krip-to-spo-rid-e-O-sis
Hep C	Hepatitis C	hep-a-TI-tis C
HPV	Human papilloma virus	HU-man PAP-i-LO-ma VI-res

Certain symptoms can occur with opportunistic infections.

- Breathing problems
- Mouth problems, such as thrush (white spots), sores, change in taste, dryness, trouble swallowing, or loose teeth
- Fever for more than 2 days
- Weight loss
- Change in vision or floaters (moving lines or spots in your vision)
- Diarrhea
- Skin rashes or itching

Tell your doctor right away if you have any of these problems. Your doctor can treat most of your HIV-related problems, but sometimes you may need to go to a specialist. Visit a dentist at least twice a year, more often if you have mouth problems.

You can learn more about how to prevent the most serious opportunistic infections by reading the brochures in the CDC Opportunistic Infections series. You can get these brochures by calling CDC-INFO at 1-800-232-4636.

How do I protect other people from my HIV?

Things you **SHOULD** do

- **Abstain from sex.** The surest way to avoid transmission of STDs, including a different strain of HIV, is to not have sexual intercourse.
- **Use condoms correctly and consistently.** Correct and consistent use of the male latex condom can reduce the risk for STD transmission. However, no protective method is 100% effective. Condom use cannot guarantee absolute protection against any STD.

- If you are allergic to latex, you can use polyurethane condoms.
- Condoms lubricated with spermicides are no more effective than other lubricated condoms in protecting against the transmission of HIV and other STDs.
- If you use condoms incorrectly, they can slip off or break, which reduces their protective effects. Inconsistent use, such as not using condoms with every act of intercourse, can lead to STD transmission because transmission can occur with just one act of intercourse.
- **Use protection during oral sex.** A condom or dental dam (a square piece of latex used by dentists) can be used. Do not reuse these items.
- **Tell others that you have HIV.**
 - Tell people you've had sex with. This can be difficult, but they need to know so they can get the help they need. Your local public health department may help you find these people and tell them they have been exposed to HIV. If they have HIV, this may help them get care and avoid spreading HIV to others.
 - Tell people you are planning on having sex with. Practicing safe sex will help protect your health and that of your partners.
 - If you are a man and had sex with a woman who became pregnant, you need to tell the woman that you have HIV, even if you are not the father of the baby. If she has HIV, she needs to get early medical care for her own health and her baby's health.

Things you should NOT do

- **Don't share sex toys.** Keep sex toys for your own use only.
- **Don't share drug needles or drug works.** Use a needle exchange program if one is available. Seek help if you inject drugs. You can fight HIV much better if you don't have a drug habit.
- **Don't donate blood, plasma, or organs.**
- **Don't share razors or toothbrushes.** HIV can be spread through fresh blood on such items.

Is there special advice for women with HIV?

Yes. If you are a woman with HIV, your doctor should check you for STDs and perform a Pap test at least once a year.

As a woman with HIV, you are more likely to have abnormal Pap test results. Infection with HIV means your body is less effective in controlling all types of viruses. The human papilloma virus (HPV) is a specific virus that can infect cervical cells (the cells that the Pap test looks at). Your doctor may recommend a special test that can look for HPV as part of your exam. If your Pap test result is abnormal, your doctor may need to repeat it or do other tests. If you have had an abnormal Pap test result in the past, tell your doctor.

If you are thinking about avoiding pregnancy or becoming pregnant, talk with your doctor. You might ask some of the following questions:

- What birth control methods are best for me?
- Will HIV cause problems for me during pregnancy or delivery?
- Will my baby have HIV?
- Will treatment for my HIV infection cause problems for my baby?

- If I choose to get pregnant, what medical and community programs and support groups can help me and my baby?

If you become pregnant, talk to your doctor right away about medical care for you and your baby. You also need to plan for your child's future in case you get sick.



Your HIV treatment will not change very much from what it was before you became pregnant. You should have a Pap test and tests for STDs during your pregnancy. Your doctor will order tests and suggest medicines for you to take. Talk with him or her about all the pros and cons of taking medicine while you are pregnant.

Talk with your doctor about how you can prevent giving HIV to your baby. It is very important that you get good care early in your pregnancy. The chances of passing HIV to your baby before or during birth are about 1 in 4, or 25%, but treatment with antiretroviral medicines has been shown to greatly lower this risk. Your doctor will want you to take these medicines to increase your baby's chance of not getting HIV.

Although you are pregnant, to avoid catching other diseases and to avoid spreading HIV, you should still use condoms each time you have sex. Even if your partner already has HIV, he should still use condoms.

After birth, your baby will need to be tested for HIV, even if you took antiretroviral medicines while you were pregnant. Your baby will need to take medicine to prevent HIV infection and PCP. Talk with your doctor about your baby's special medical needs. Because HIV infection can be passed through breast milk, you should not breast-feed your baby.

Where can I find help in dealing with HIV?

If you are living with HIV or AIDS, you may need many kinds of support: medical, emotional, psychological, and financial. Your doctor, your local health and social services departments, local AIDS service organizations, and libraries can help you in finding all kinds of help, such as the following:

- Answers to your questions about HIV and AIDS
- Doctors, insurance, and help in making health care decisions
- Food, housing, and transportation
- Planning to meet financial and daily needs
- Support groups for you and your loved ones
- Home nursing care
- Help in legal matters, including Americans with Disabilities Act (ADA) claims
- Confidential help in applying for Social Security disability benefits

You can also get help by calling CDC-INFO at 1-800-232-4636.

Many people living with HIV feel better if they can talk with other people who also have HIV. Here are some ways to find support.

- Contact your local AIDS service organization. Look under “AIDS” or “Social Service Organizations” in the yellow pages of your telephone book.
- Contact a local hospital, church, or American Red Cross chapter for referrals.
- Read HIV newsletters or magazines.
- Join support groups or Internet forums.
- Volunteer to help others with HIV.

- Be an HIV educator or public speaker, or work on a newsletter.
- Attend social events to meet other people who have HIV.

Today, thousands of people are living with HIV or AIDS. Many are leading full, happy, and productive lives. You can too if you work with your doctor and others and take the steps outlined in this booklet to stay healthy.



More information about living with HIV or AIDS is available as follows:

Free referrals or information

CDC-INFO

(800) CDC-INFO (232-4636)

TTY: (888) 232-6348

English and Spanish

24 hours/day, 7 days/week

CDC Division of HIV/AIDS Prevention Internet

www.cdc.gov/hiv/dhap.htm

Free materials

CDC National Prevention Information Network

PO Box 6003

Rockville, MD 20849-6003

(800) 458-5231

(301) 562-1098 (International)

www.cdcpin.org

Free HIV/AIDS treatment information

AIDSinfo

(800) 448-0440

www.aidsinfo.nih.gov

Project Inform

(800) 822-7422

Information on drugs in clinical trials

AIDSinfo

(800) 448-0440

www.aidsinfo.nih.gov

Social Security benefits

Social Security Administration

(800) 772-1213

(You may request a personal earnings and benefits estimate statement to help you estimate the retirement, disability, and survivor benefits you are entitled to.)